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Social and human rights questions: genetic privacy and non-discrimination

Information and comments received from Governments and relevant international organizations and functional commissions pursuant to Economic and Social Council resolution 2001/39

Report of the Secretary-General**

Addendum

Information and comments provided by Member States

Argentina

1. The Advisory Council of the National Institute to Combat Discrimination, Xenophobia and Racism (INADI) received the note transmitted by the Directorate for International Organizations of the Ministry of Foreign Affairs, International Trade and Worship requesting the Advisory Council's comments on Economic and Social Council resolution 2001/39 entitled "Genetic privacy and non-discrimination".

2. The Council accorded particular attention to the following international documents:

- Economic and Social Council resolution 2001/39 entitled "Genetic privacy and non-discrimination";
- the Universal Declaration on the Human Genome and Human Rights;
- the Council of Europe Convention on Human Rights and Biomedicine;
- the Convention on the Rights of the Child (arts. 7 and 8).

* E/2003/100.
** The information contained herein was received after the submission of the main report.

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3. It also took into consideration the corresponding national legislation:

- Act No. 25,311 on the establishment of genetic data;
- Act No. 23,592 on discriminatory acts;
- the Constitution and national legislation relating to the topic in question.

4. Lastly, INADI having solicited the opinion of the Committee on Ethics in Science and Technology, Secretariat of Science, Technology and Productive Innovation, Ministry of Education, on the topic in question and analysed the Committee's views with particular interest, endorses in substance the conclusions reached by the author of the report, Dr. Aida Kemelmajer de Carlucci, and the report is, accordingly, incorporated into that of INADI as reflecting a common position.*

Report of the National Institute to Combat Discrimination, Xenophobia and Racism of the Argentine Republic

5. On the occasion of drawing up the present report and registering its express support for that of the Committee on Ethics in Science and Technology, the National Institute to Combat Discrimination, Xenophobia and Racism (INADI) considers it imperative to make some basic comments on various specific issues.

6. The deciphering of the sequence of the human genome has augmented the search for genes whose variants or mutations are not the direct cause of diseases but which make an individual predisposed to spread them or contract diseases, by comparison with others who do not carry such variants.

7. In this way, an effort is made to predict the risk of contracting diseases where the genetic determinant is not 100 per cent but is conditioned by the specific type of environment (physical, biological, external and/or internal of the organism) in which the genetic variant manifests itself. For example, cardiovascular and autoimmune diseases, schizophrenia, bipolar depressions, etc., are highly complex diseases in which genetics may have a certain weight but is unfailingly conditioned by the environment. The phenotype, i.e., what is visible in an individual (his physiological form and behaviour), is a consequence of the interaction of the genotype (genes, genome) with the environment. A given genotype may produce different phenotypes in different environments, within certain limits. Failure to take this concept into account results in vast problems, of which the most important is genetic hyperdeterminism, i.e., the unjustified preconception that everything is determined by genes and that there are genes for everything — genes to explain homosexuality, criminality, corruption, learning, intelligence and — why not — poverty.

8. The immediate danger of ignoring the environmental factor leads to the error of considering genetic determinism to be a fact, which then opens the door to discrimination — denying individuals life or health insurance or excluding them from employment not on the basis of the certain knowledge that they will suffer from any given illness, but rather based on the assumption that there is some probability of their suffering from that illness.

* INADI reserves its position regarding compulsory use of genetic data against accused persons in criminal cases, since there is a risk of violating the principle "Nemo tenetur armare adversarium contra se".

9. In this context, the privacy of individual genetic information is a right which must be inalienable.

10. Genetic hyperdeterminism is not only a prevailing misconception among the majority of the population, which of course knows nothing of genetics and the processes which affect personality development, but, more seriously, it is also a school of thought in clinical research and modern pharmaceutics that feverishly seeks the genetic variants "associated" with illnesses or disorders which have no proven genetic origin. We believe such research is wrongheaded and contributes to unrealistic expectations among the population and investors, given that it is unlikely that the search for the genes "responsible" will succeed in the case of illnesses whose hereditary nature has not previously been clinically proven. Mapping of the human genome does not authorize anyone to stigmatize individuals as the irreversible product of their pre-ordained genetic make-up. Our genes give us the power of speech but do not choose the language we speak, give us the power to appreciate music but do not choose the type of music, give us the power to love but do not choose our loved one.

11. The various kinds of intelligence, our capabilities, emotions and actions are the result of an acculturation process which is not recorded in any gene and is strongly influenced by the family, social and economic environment in which we live.[1]

12. INADI wishes to use the occasion of this report to reject any use of biology to defend race-based behaviours. No one may consider another person to be inferior because of his/her genetic code; legislation must be further reinforced to ensure that all persons are treated equally, a concept first included in the Declaration of the Rights of Man and of Citizens.

13. The report also provides an opportunity to note that culture, tradition, the economy, education, climate, and the urban, rural and family, environment greatly influence the development of a certain type of intelligence, irrespective of the genes, which determine such ridiculously artificial characteristics as the colour of the skin, etc. While the ability to learn and to reason may not be totally independent of the genes, since a person's genetic make-up probably bestows a predetermined capacity for intellectual development, that hypothesis can only be accepted if the following premises are taken into account:

1. It is much more difficult in human beings than in other species to determine which portion of a phenotype is acquired and which is hereditary;

2. Even if genetic variants do exist which assist or hinder intellectual development, there is no experimental evidence that the former are more prevalent in one human group and the latter in another.

14. It must not be forgotten that article 27 of the Universal Declaration of Human Rights sets forth the principle that everyone has the right freely to participate in ... scientific advancement and its benefits. Article 15 of the International Covenant on Economic, Social and Cultural Rights contains similar language. It is important that access to biological, genetic and medical advances relating to the human genome be unrestricted. States must in the future eliminate any cultural, linguistic or other obstacles which restrict the rightful utilization of genetic material for purposes approved by international instruments.

15. With regard to the right to identity, INADI believes that it is particularly important to standardize the use of genetic information to identify the family origin of children, in accordance with article 7 of the Convention on the Rights of the Child ("The child ... shall have ... the right to know and be cared for by his or her parents."). The same holds true for article 8 of that Convention, in particular with regard to States Parties' undertaking "to respect the right of the child, to preserve his or her identity, including nationality, name and family relations as recognized by law without unlawful interference". The second paragraph of that same article states that "Where a child is illegally deprived of some or all of the elements of his or her identity, States parties shall provide appropriate assistance and protection, with a view to speedily re-establishing his or her identity". Accordingly, INADI is of the opinion that any addition to the body of law regarding that issue which respects the principles in question should be welcomed by the Member States of the United Nations.

Report of the Committee on Ethics in Science and Technology

Introduction

16. In January 2003 the National Institute to Combat Discrimination, Xenophobia and Racism (INADI) asked the Committee on Ethics in Science and Technology to deliver an opinion on the resolution dated 26 July 2001 of the United Nations Economic and Social Council entitled "Genetic privacy and non-discrimination".

17. The Committee on Ethics in Science and Technology agreed to consider the matter and asked Aída Kemelmajer de Carlucci[2] to act as Rapporteur. At its second plenary meeting of 2003, the Committee approved the report of the Rapporteur and the recommendations to INADI.

Report of the Rapporteur

18. The Rapporteur opted to carry out an explanatory analysis of the Economic and Social Council resolution on genetic privacy and non-discrimination and its relationship to the Universal Declaration on the Human Genome and Human Rights adopted on 11 November 1997 by the General Conference of the United Nations Educational, Scientific and Cultural Organization (UNESCO).[3] The need for a comparison of the two texts stems from the fact that the Economic and Social Council is an organ of the United Nations. The proposed resolution must therefore not contradict or challenge previous documents, and it must constitute a step forward, at least in implementing some of the principles laid down in fields which fall within the competence of the Council.

19. This is the method which underlies the comparison of paragraphs 1 to 5 of the resolution.

Paragraph 1 of the resolution

Urges States to ensure that no one shall be subjected to discrimination based on genetic characteristics.

20. This article echoes article 6 of the Declaration, which states that:

"No one shall be subjected to discrimination based on genetic characteristics that is intended to infringe or has the effect of infringing human rights, fundamental freedoms and human dignity."

21. The verb "to ensure" in the resolution seems to convey an intention to oblige States to ban discrimination on genetic grounds. This intention probably derives from the fact that the Declaration in effect has less force than an international convention, so a provision that would oblige States to ensure a ban on discrimination could be a step forward. However, the use of the verb "to urge" leaves the situation unchanged.

22. The Declaration bans discrimination only in instances in which fundamental rights and freedoms are threatened. The resolution, by contrast, would prohibit discrimination on any grounds whatsoever.

23. However, because the resolution has been proposed by the Economic and Social Council, the text should specify the areas within the Council's competence that are covered by the ban on discrimination.

24. The provisional conclusion is that this article of the resolution has no discernible purpose, because the Declaration expresses the same principle in a more suitable way.

Paragraph 2 of the resolution

Also urges States to protect the privacy of those subject to genetic testing and to ensure that genetic testing is done with the prior, free, informed and express consent of the individual or authorization obtained in the manner prescribed by law and in accordance with public international law and the international law of human rights.

25. The equivalent provision is article 5 of the Declaration, which states that:

(a) Research, treatment or diagnosis affecting an individual's genome shall be undertaken only after rigorous and prior assessment of the potential risks and benefits pertaining thereto and in accordance with any other requirement of national law;

(b) In all cases, the prior, free and informed consent of the person concerned shall be obtained. If the latter is not in a position to consent, consent or authorization shall be obtained in the manner prescribed by law, guided by the person's best interest;

(c) The right of each individual to decide whether or not to be informed of the results of genetic examination and the resulting consequences should be respected.

26. An analysis of the texts leads to the following conclusion:

The expression "*dado con conocimiento de causa*" (informed) used in the Spanish version of the resolution does not seem to be correct, and the reference to the law is not necessary.

It would therefore be useful to maintain such accepted and well-known terms as are used in the following article: "In all cases, the prior, free, and sufficiently informed consent of the person concerned shall be obtained. If the latter is not in a position to

consent, consent or authorization shall be obtained in the manner prescribed by the law, guided by the person's best interest".

27. This article could be applied to genetic testing by using a formula such as: "The circumstances under which testing may be judicially authorized with a view to providing essential evidence, and the possible consequences of an unwarranted refusal to submit to such testing, shall be determined by law on a case-by-case basis."

28. The use of this or a similar formula would have the advantage of: (a) referring to the circumstances in which testing is imposed by the law in order to provide evidence in certain judicial proceedings; (b) making it clear that those circumstances are exceptional; (c) requiring the law to set forth the possible consequences of an unwarranted refusal (with respect to a paternity suit, for example, the law will consider a person's unjustified refusal as serious evidence against him).

29. In decisions Nos. 103/1990 and 22/1990, the Spanish Constitutional Court stated that:

> "In cases where testing is provided for by law and approved by the judicial authority, with reasons given, in the context of a judicial proceeding, the right to integrity is not infringed.
>
> In these types of proceedings, there is a conflict between the fundamental rights of the various parties involved. In paternity cases, there is no doubt that the social interest and the interest of public order, which underlie declarations of paternity, where what is at stake are the rights of children to support and inheritance (specially protected by article 39.2), are the dominant ones, or that they transcend the rights claimed by the individual concerned where what is also at stake is the certainty of a judicial pronouncement. The constitutional rights to privacy and physical integrity cannot become a form of endorsement of impunity, where the burdens and duties resulting from behaviour closely linked to respect for possible family bonds are ignored."

30. In order to ensure that the constitutional rights of the person concerned are not infringed by the measure, there must be agreement on the need for the following:

(a) The testing should be performed under proper conditions by a medical professional;

(b) There must be a reason provided for by law that justifies judicial intervention;

(c) The evidence cannot be obtained by other means of obtaining evidence that are less harmful to the physical integrity of the defendant;

(d) Such testing should not be carried out if it may pose a serious risk or cause harm to the health of the person who is to undergo testing;

(e) The judicial measure must maintain a proper balance between the intervention which affects the privacy and physical or moral integrity of the person concerned and the purpose that it serves.

31. The National Genetic Databank was created in Argentina pursuant to Act No. 23.511 (of 1987), with a view to obtaining and storing genetic information to facilitate the resolution and elucidation of paternity-related disputes. However, the

Databank also performs wider functions; in general, the requisite genetic tests are performed by the immunology service of the Durand Hospital. Article 4 of this Act provides that "Refusal to submit to the necessary tests and analyses shall constitute evidence against the contentions of the unwilling party." National jurisprudence has for the most part tended to convert such an unwarranted refusal into a real presumption against the unwilling party.

32. The final part of paragraph 2 of the resolution refers both to public international law and to the international law of human rights, thereby establishing an international framework for national judicial authorities.

33. Against this background, the law can infer consequences from a refusal to submit to testing; however, forced submission is difficult to imagine, particularly in criminal proceedings. The issue has been widely discussed in legal writing and case-law. The Argentine Federal Court, after some hesitation, has accepted such evidence, even when produced under duress, in criminal proceedings.

34. There is no question as to the relevance of the reference to international human rights law; however, the appropriateness of the reference to public international law in general is unclear.

35. Argentine law is restricted by international human rights law (article 75, paragraph 22, of the Constitution).

36. In accordance with the arguments put forward, the sentence in question should be replaced by the following:

> "Under no circumstances may testing be carried out in violation of the principles of international human rights law".

Paragraph 3 of the resolution

> *"Invites States to take appropriate specific measures, including through legislation, to prevent the use of genetic information and testing leading to discrimination or exclusion against individuals or members of their families or other persons with whom they may share certain genetic characteristics, in all areas, in particular in social, medical or employment-related areas, whether in the public or private sector."*

37. This provision corresponds to article 7 of the Declaration, which states that:

> *"Genetic data associated with an identifiable person and stored or processed for the purposes of research or any other purpose must be held confidential in the conditions set by law."*

38. The resolution makes the Declaration more explicit, but the wording could perhaps be improved.

39. The phrase "including through legislation" would appear to suggest that law is an exceptional means of protection, when in fact it is one of the primary means.

40. Three areas are mentioned: social, medical or employment-related. It is unclear what meaning is attached to "social" as a distinct category. Can we assume that the medical and employment-related areas are outside the social area?

41. In any event, it would be preferable to refer specifically to insurance contracts, an area in which it is undeniable that discrimination can occur, with extremely serious consequences.

Paragraph 4 of the resolution

> *"Calls upon States to promote, as appropriate, the development and implementation of standards providing greater protection with regard to the collection, storage, disclosure and use of genetic information taken from genetic tests that might lead to discrimination or invasion of privacy."*

42. The provision appears to distinguish between two types of State action: "development" and "implementation" of standards (with the qualifier "as appropriate"). The term "development" is not commonly used in legal language and should perhaps be replaced by "approval" (*sanción*).

43. The provision correctly mentions privacy. It might be appropriate to include "family privacy", since international conventions distinguish between these two aspects of privacy.

Paragraph 5 of the resolution

> *"Urges States to continue to support research in the area of human genetics and biotechnology, subject to accepted scientific and ethical standards and to the potential benefit of all, especially the poor, emphasizing that such research and its applications should fully respect human dignity, freedom and human rights, as well as the prohibition of all forms of discrimination based on genetic characteristics."*

44. This provision is drafted along the same lines as article 17 of the Declaration, which states as follows:

> *"States should respect and promote the practice of solidarity towards individuals, families and population groups who are particularly vulnerable to or affected by the disease or disability of a genetic character. They should foster, inter alia, research on the identification, prevention and treatment of genetically-based and genetically-influenced diseases, in particular rare as well as endemic diseases which affect large numbers of the world's population."*

45. In terms of grammar and style, the resolution appears to be drafted less carefully than the Declaration (e.g., in the Spanish version, paragraph 5 begins with "*que sigan apoyando*" (to continue to support), but then says "*y teniendo presentes*" (emphasizing)).

46. It correctly mentions the poor, without any euphemisms.

47. The last sentence of the paragraph, which reads "as well as the prohibition of all forms of discrimination based on genetic characteristics", is redundant, since it reiterates a concept referred to in the other paragraphs.

48. It correctly mentions human dignity, a cherished ethical concept, but we should note the superiority of the formula contained in the Council of Europe Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine, which refers to the obligation to protect

not only the dignity but also the identity of human beings. The European text, which could be adapted for the purposes of the draft resolution, states as follows:

> *"Parties to this Convention shall protect the dignity and identity of all human beings and guarantee everyone, without discrimination, respect for their integrity and other rights and fundamental freedoms with regard to the application of biology and medicine.*
>
> *Each Party shall take in its internal law the necessary measures to give effect to the provisions of this Convention."*

An omitted issue

49. One of the thorniest issues in the area of genetic information relates to the economic gains from patenting.

50. This is a very controversial issue which involves private interests and is generating a great deal of discussion. For these reasons, in dealing with an issue that has such an impact on its area of competence, the Economic and Social Council would need to find a formula which incorporates the principle of fair access to gains and protection from risks.

51. The Declaration chose a transactional formula which, while not completely appropriate from the standpoint of developing countries, incorporates their input. Article 4 of the Declaration states as follows:

> *"The human genome in its natural state shall not give rise to financial gains."*

52. In sum, a comparison of the Economic and Social Council resolution on "Genetic privacy and non-discrimination", adopted in 2001, with the Universal Declaration on the Human Genome and Human Rights, adopted by UNESCO in 1997, suggests the following remarks:

(a) Paragraph 1 of the resolution should specify the cases in which genetic non-discrimination applies;

(b) With regard to protection against genetic discrimination, it should be noted that article 6 of the Declaration expresses this concept in clearer and more appropriate language than paragraph 1 of the resolution;

(c) Paragraph 2 of the resolution should not only urge States to protect the privacy of those subject to genetic testing, but should also call upon States to adopt laws enumerating the exceptional cases in which testing may be ordered by the courts, even without a person's consent;

(d) The last part of paragraph 2 of the resolution refers to public international law, but it would be more relevant to refer to international human rights law;

(e) Paragraph 3 of the resolution should incorporate a specific reference to the prohibition of discrimination in the area of insurance contracts;

(f) In paragraph 4 of the resolution, the word "development" should be replaced by "approval", which is more appropriate to legal language;

(g) Paragraph 4 of the resolution should include the protection not only of individual privacy but also of family privacy, since international conventions distinguish between these two aspects of privacy;

(h) Paragraph 5 of the resolution should mention not only respect for human dignity, but also respect for the identity of human beings;

(i) The resolution omits the controversial issue of patenting and the private interests linked to genetic information. This problem should be considered because it is a matter for the Council and because of the consequences and risks which it implies.

Recommendations

53. In view of the foregoing, the Committee on Ethics in Science and Technology recommends that INADI draw attention to the limitations, omissions and insufficient rationale for the resolution, in that it does not represent any progress with respect to the Universal Declaration on the Human Genome and Human Rights.

54. In particular, the Committee recommends that INADI point out that in terms of preventing discrimination, the resolution:

(a) Does not clearly distinguish cases in which the privacy of genetic information should be guaranteed in order to avoid discrimination against individuals (insurance, medical assistance, employment situations) from those in which genetic information is an instrument for preventing impunity and contributes to a better implementation of justice (criminal, identity and paternity cases);

(b) Does not deal with the topic of patenting and the private interests linked to genetic information, a matter of direct concern to the Council, and, accordingly, does not include instruments which might have prevented discrimination, injustice and inequity in access to knowledge of benefit to humanity.

Notes

[1] Alberto Kornblihtt, "La humanidad del genoma, el hombre y la biología molecular", *Encrucijadas*, University of Buenos Aires, vol. I, No. 5, March 2001.

[2] Aída Kemelmajer de Carlucci is a lawyer and Doctor of Law, a fellow of the National Academy of Law and Social Sciences of Buenos Aires and a correspondent of the National Academy of Law and Social Sciences of Córdoba. She is a Minister at the Supreme Court of Justice of Mendoza and a senior lecturer in civil law at the University of Mendoza and the National University of Cuyo. She is a professor at the University of Paris II and XII (France) and the University of Genoa (Italy) and an honorary professor at the University of San Marcos and San Martín de Porres (Peru). She is a lecturer in Argentina and abroad and has written many books on legal issues. She received the Konex Platinum Award in 1996.

[3] The Economic and Social Council resolution will hereinafter be referred to as "the resolution" and the Universal Declaration on the Human Genome and Human Rights will be referred to as "the Declaration".